ROLE OF THE FAMILY IN

TREATMENT PROGRAMS

The involvement of family members in child and adolescent services is crucial to successful treatment outcomes (Kutash & Rivera, 1995; Pfeifer & Strzelecki, 1990). The effectiveness of services for children and adolescents is believed to hinge less on the particular type of treatment provided than on the participation of the family in planning, implementing, and evaluating the services. Research indicates that, for children with serious mental health problems, the more the family participates in planning services, the more likely the family members are to feel that their child's needs are being met (Koren et al., 1997) and that they have control over the child's treatment (Curtis & Singh, 1996; Thompson et al., 1997). Furthermore, family participation promotes an increased focus on families, the provision of services in natural settings, a greater awareness of cultural sensitivity, and a community-based system of care. There is also a growing body of research that has found that family participation improves the delivery of services, as well as their outcomes (Knitzer et al., 1993).

Nevertheless, there is a growing body of evidence indicating that children from vulnerable populations (children of single mothers, children who live in poverty, and minority children) who exhibit the most serious problems are also the most likely to terminate their treatment early (Kadzin & Mazurick, 1994). Additional research is necessary to determine the factors that contribute to this early termination. In recognition of this problem, however, it is important for mental health providers to ensure that these families are actively recruited and engaged in the services that the child receives in order to maximize the potential for successful outcomes.

This goal is complicated, however, by the fact that both families and providers may be confused and hesitant about the role that family members should play in treatment efforts. This is further complicated by systemic barriers that may preclude families from fully participating in the procurement of high-quality mental health services for their children. One such barrier is the relinquishment of custody of children for obtaining mental health services.

National surveys conducted by the Bazelon Center for Mental Health Law, the National Alliance for the Mentally Ill (NAMI), the Federation of Families for Children's Mental Health, and Maryland's Coalition of Families for Children's Mental Health state that between 23 and 27% of families of children with Serious Emotional Disturbance (SED) report being encouraged to relinquish custody in order to obtain needed services for their children (Virginia State Executive Council, 2004). These families typically lack the financial resources to obtain appropriate mental health services for their children. In order to gain access to publicly-funded mental health services, many of these families pursue services available within the child welfare/foster care system (Virginia State Executive Council). To receive these services, families may be forced to relinquish custody of their child to a child welfare agency in order to access funding. Approximately 20% of those who have children with SED do in fact relinquish custody (Virginia State Executive Council). In November of 2007, Virginia confronted this issue by issuing interagency guidelines to address this practice. These guidelines provide guidance to agencies regarding the authorization of needed services to children with emotional and behavioral issues so that families are not forced to

relinquish custody. Unfortunately, other states are continuing to grapple with this issue. Other barriers facing families may include the availability of appropriate services, the availability of culturally competent services, and the lack of child psychiatrists.

In an attempt to combat this problem, researchers have identified six broad roles that families should play in the treatment process. Members of the family should act as contributors to the environment, recipients of service, partners in the treatment process, service providers, advocates, and evaluators and researchers (Friesen & Stephens, 1998). It is important that family members assume each of these roles in order to provide the effective support network that is necessary for the child's continued improvement.

Freisen & Stephens (1998) outline these six roles for families:

Contributors to the Environment – Family members are the key component of the environment in which a child resides. Consequently, treatment providers often try to identify ways in which the behavior and interactions between family members influence the child's emotional and behavioral problems. With the assistance of the treatment provider, family members should consider ways to improve the home environment and the relationships in the family in order to provide the child with the most stable, supportive environment possible. In addition, family members should seek external support from their extended family and members of the community in order to reduce the stress of raising a child with emotional or behavioral difficulties.

Recipients of Service – Family members are also an important part of the therapeutic process. Service providers often focus on the family unit as a whole, creating interventions and strategies that target the health of the entire family. These interventions are intended to assess the strengths and weaknesses that exist within the family structure, to enhance the well-being of parents and other family members, and to help families locate support mechanisms in the community.   The provider also assists family members in developing the skills necessary to support the special needs of the child. Services may include supportive counseling, parental training and education, development of coping skills and stress management techniques, respite care, parental support groups, transportation, and financial assistance.

Partners in the Treatment Process – Family members also serve as equal contributors in the problem-solving process. They should work with treatment providers to identify the goals of treatment and to plan realistic strategies to achieve these goals. Additionally, family members should play a key role in implementing these strategies to ensure that the treatment goals are met. When performing these functions, caregivers should not be afraid to ask questions and to voice their opinions and preferences. It is crucial that they are fully informed and that their preferences are considered in all treatment decisions.

Service Providers – The treatment process is incomplete without the direct services provided to the child by family members. They are responsible for providing emotional support and information to the child and other family members, and for filling in the gaps in the services being received by the child. Furthermore, they often coordinate the services being received by the child by requesting, convening, and scheduling meetings, and transporting the child to appointments. It is a crucial role, the importance of which cannot be understated. Parents and caregivers need to remain vigilant and involved in all aspects of the child's treatment. This includes keeping all follow-up appointments,

becoming knowledgeable about any prescribed medications, and keeping track of all treatments that have been tried unsuccessfully.

Advocates – Family members often serve as the child's only voice in the mental health system. They should therefore actively advocate for the child in order to ensure that he receives the appropriate services, and should voice any concerns regarding undesirable practices and policies. There are several local, state, and national organizations that can assist parents and caregivers in these efforts, allowing them to serve as part of a larger voice in the community.

Evaluators and Researchers – It is important that families participate in research and evaluation activities so that their opinions can be heard regarding which treatments and services are most beneficial and convenient. The input of family members is crucial to ensure that all children receive services that are efficient and effective. While much of this research requires the involvement of the family for a significant length of time, the input of caregivers and other family members is extremely important.

Families play important supporting roles in combating mental health disorders. Although the child is the most important focus of treatment, family members can help by offering support, and encouragement, and by creating a favorable environment. Family members can help their child while they are receiving treatment by recognizing and praising small achievements, modifying expectations during stressful periods, measuring progress on the basis of the improvements made, and being flexible, while trying to maintain a normal routine (Psychiatry 24x7.com, 2005).

The following information is attributed to the Substance Abuse and Mental Health Services Administration (SAMHSA) (2000). Families must recognize that, while they are obtaining services for their child, they are the experts in understanding the following:
- how their child responds to different situations;
- their child's strengths and needs;
- what their child likes and dislikes; and
- what has worked and not worked in helping their child.

Families are ultimately responsible for determining what services and supports their children receive. Thus, families must communicate to service providers their children's strengths and weaknesses, as well as their priorities and expectations. Family members must also inform their service provider as soon as they realize that treatment is not working so that appropriate modifications can be made (SAMHSA, 2000). It is crucial to remember that children are different and their needs are also very diverse.

These recommendations also hold true for children who come in contact with the juvenile justice system. Family involvement is particularly critical for these youth to ensure positive outcomes (Osher & Hunt, 2002). It is imperative that families remain involved so they provide information on the child's diagnosis and treatment history, use of medications, the families' ability to participate in treatment, special circumstances that affect their child, and their child's education history and status (including whether the child is enrolled in special education) (Osher & Hunt). Ideally, families should remain involved at each stage of the system so they can be involved in decision-making and treatment (Osher & Hunt). Families and juvenile justice officials must cooperate to ensure that all have mutual responsibility for the child's outcomes (Osher & Hunt).

Families must remain actively involved in all aspects of their child's mental health treatment. Without family involvement, it is extremely difficult for service providers to ensure that the gains achieved by the child in treatment are maintained and solidified. Moreover, the combined efforts of service providers, family members, and advocates are necessary to ensure that the services provided in the community effectively meet the needs of all children and families. It is important that parents and caregivers understand the results of any evaluation, the child's diagnosis, and the full range of treatment options. If parents are not comfortable with a particular clinician, or treatment option, or are confused about specific recommendations, they should consider a second opinion.

The guide to parents and caregivers which follows was developed by the American Academy of Child & Adolescent Psychiatry (AACAP).

Questions that Parents or Caregivers
Should Ask About Treatment Services

Before a child begins treatment, parents should ask the following:
- Does my child need additional assessment and/or testing (medical, psychological etc.)?
- What are the recommended treatment options for my child?
- Why do you believe treatment in this program is indicated for my child? How does it compare to other programs or services which are available?
- What are the advantages and disadvantages of the recommended service or program?
- What will treatment cost, and how long will it take?
- How much of the cost is covered by insurance or public funding? Will we reach our insurance limit before treatment is completed?
- How will my child continue education while in treatment?
- Does my child need medication? If so, what is the name of the medication that will be prescribed? How will it help my child? How long before I see improvement? What are the side effects which commonly occur with this medication?
- What are the credentials and experience of the members of the treatment team?
- How frequently will the treatment sessions occur?
- Will the treatment sessions occur with just my child or the entire family?
- How will I be involved with my child's treatment?
- How will we know if the treatment is working? What are some of the results I can expect to see?
- How long should it take before I see improvement?
- What should I do if the problems get worse?
- What are the arrangements if I need to reach you after-hours or in an emergency?
- As my child's problem improves, does this program provide less intensive/step-down treatment services?
- How will the decision be made to discharge my child from treatment?
- Once my child is discharged, how will it be decided what types of ongoing treatment will be necessary, how often, and for how long?

Source: American Academy of Child & Adolescent Psychiatry (AACAP), 2000.

Supplementary Issues for Families
Continuous 24-hour-a-day news coverage of events, such as natural disasters, catastrophic events, and crime reports, may cause children to experience stress, anxiety, and fears (AACAP, 2002).

According to the American Academy of Child & Adolescent Psychiatry (AACAP), children may be easily influenced and unable to distinguish the difference between reality and the fantasy presented on television (2001). As a result, children may be exposed to behaviors and attitudes that can be overwhelming and difficult to understand (AACAP). Caregivers should understand that violent media images may have a greater impact upon children with emotional and behavioral issues than might otherwise be the case (AACAP, 2006).

Systems of Care and Family Involvement

Family involvement is a vital component within a system of care. A system of care is "...a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families" (Stroul, 2002). A system of care is not a program but a philosophy. The information in this section is attributed to *Systems of Care: A Framework for System Reform in Children's Mental Health* (Stroul).

The primary values of the system of care philosophy are that services for children are:
- Community-based;
- Child-centered and family-focused; and
- Culturally competent.

In a system of care, family involvement is vital because families are designated partners in the design of effective mental health services and supports. Families have a primary decision-making role in the care of their own children, as well as in the policies and procedures governing care for all children in their communities. This includes:
1. Choosing supports, services, and providers;
2. Setting goals;
3. Designing and implementing programs;
4. Monitoring outcomes;
5. Partnering in funding decisions; and
6. Determining the effectiveness of all efforts to promote the mental health and well-being of children and youth.

Systems of care rely upon family and youth experiences and utilize families' expertise to steer decision-making in service and system design, operation, and evaluation. In recent years, studies have been designed to assess the impact of family partnerships upon child and family outcomes. The findings reveal that children who had families that were involved in their treatment experienced improved educational outcomes and well-being, as well as reduced length of stay in out-of-home placements and residential settings (Jivanjee, et al., 2002). Systems of care establish partnerships that work because the system is guided by the family.

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Organizations/Weblinks - General
Center for Effective Collaboration and Practice
Spanish services are available.
888-457-1551
http://cecp.air.org

Florida Mental Health Institute
813-974-4661
http://www.fmhi.usf.edu

National Alliance for the Mentally Ill (NAMI)
Spanish services are available.
703-524-7600
http://www.nami.org

National Mental Health Association (NMHA)
Spanish services are available.
703-838-7529
http://www.nmha.org

National Resource Network on Child and Family Mental Health Services
202-408-9320
http://www.wbgh.com

National Technical Assistance Center for Children's Mental Health
Spanish services are available.
202-687-5000
http://www.dml.georgetown.edu

Research & Training Center on Family Support and Children's Mental Health
800-628-1696
http://www.rtc.pdx.edu

U.S. Department of Education
Office of Special Education Programs
Spanish services are available.
202-205-5507
http://www.ed.gov/about/offices/list/osers/index.html?src=mr

U.S. Department of Health and Human Services
Substance Abuse and Mental Health Services Administration (SAMHSA)
National Mental Health Information Center (*Spanish services are available.*)
Child, Adolescent and Family Branch, Center for Mental Health Services
800-789-2647
http://www.mentalhealth.samhsa.gov/child

Virginia Resources
Attorney General, Virginia Office of
804-786-2071
http://www.oag.state.va.us

Mental Health America of Virginia
http://www.mhav.org/home.html

National Alliance for the Mentally Ill Virginia (NAMI Virginia)
http://www.nami.org/MSTemplate.cfm?Section=Homepage60&Site=NAMI_Virginia&Template=/ContentManagement/ContentDisplay.cfm&ContentID=51980

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2025 East Main Street, Suite 107 ̶ Richmond, VA 23223
804-649-8481 Ext. 102; Toll free: 888-604-2677
http://www.medhomeplus.org

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